

Durham Research Online

Deposited in DRO:

24 May 2012

Version of attached file:

Published Version

Peer-review status of attached file:

Unknown

Citation for published item:

Burges Watson, D.L. and Lewis, S. and Buckley, J. (2011) 'John's cheese sandwich : taking on PPI, with relish.', INVOLVE newsletter, Autumn . pp. 9-10.

Further information on publisher's website:

<http://www.invo.org.uk/posttypenewsletter/autumn-2011/>

Publisher's copyright statement:

Deposited with the kind permission of the part of INVOLVE, part of the National Institute of Health Research (NIHR).

Additional information:

Use policy

The full-text may be used and/or reproduced, and given to third parties in any format or medium, without prior permission or charge, for personal research or study, educational, or not-for-profit purposes provided that:

- a full bibliographic reference is made to the original source
- a [link](#) is made to the metadata record in DRO
- the full-text is not changed in any way

The full-text must not be sold in any format or medium without the formal permission of the copyright holders.

Please consult the [full DRO policy](#) for further details.

of health research, policy implementation and issues around implementation of the findings of research. I have a greater appreciation of the financial constraints and more confidence to contribute and offer my opinion. I have a better understanding of the importance of research design and my knowledge of PPI has grown – it is now part of my lived experience and expertise.

Since that first meeting in 2004, I have also been a PPI member on a National Institute for Health Research (NIHR) commissioning panel for the Research for Patient Benefit Programme, as well as a PPI sub panel member for the Programme Grants for Applied Research and a lay member on three publicly funded research projects. All have been good experiences but I do not think I would have participated in any of these without that early positive experience.

Contact: Sandra Paget
Email: sgpaget@me.com

For more information about the research initiative for Long Term Neurological Conditions visit www.ltnc.org.uk

John's cheese sandwich: taking on PPI, with relish

By Duika Burges Watson, Sue Lewis and John Buckley

John's face said it all. Months before, the chef had promised him a cheese sandwich, and there it was in front of him. He tucked into it with relish, and barely paused until the plate was clean.

What could possibly be special about a cheese sandwich? For John, it was the first taste of his favourite snack for more than three years, since the treatment that had saved his life left him with eating difficulties that may stay with him for the rest of his life. The radiotherapy received

by head and neck cancer patients often results in saliva loss and narrowing of the gullet, leaving them with eating disorders, including problems with food texture and taste. As a result, they can lose interest in food (causing nutritional problems for some) and eating socially is embarrassing, which leaves survivors feeling isolated and families confused.

Because of the scientific and practical complexity of the problem – each survivor seems to have a slightly different response to foodstuffs – very little research has been done in this area. However, Duika believed that molecular gastronomy might have something to offer. She found a chef (Sean Wilkinson) with the right expertise, and together they started to ask survivors and clinicians more about the problem. In April 2011, a project committee of John and his wife, an interdisciplinary academic team and the region's Patient and Public Involvement (PPI) Officer, met for the first time. John agreed to be the project's recruitment co-ordinator, and also mentioned the cheese sandwich; he cannot manage bread or cheese because he has no saliva, and a traditional cheese sandwich was what he missed the most. The chef promised him a sandwich that he could eat.

Although the team was still unsure about the scope of the problem, or that a research question should be formulated without further survivor input. A small amount of funding from the Wolfson Research Institute, Durham University, enabled us to run three PPI workshops over the summer. Survivors and their partners were invited along to a community centre chosen for its geographical convenience and because it had a suitable kitchen – these workshops would go further than a simple focus group. Together, the group watched short videos on the science of molecular gastronomy, and on case studies, which prompted sometimes emotional discussion. The chef led light-hearted demonstrations, altering the texture of foods and even of the liquid 'sip feeds' **Continued >>**

that many survivors depend on. Survivors gave feedback – not all positive – and discussions were recorded on audio and video (with consent). The relaxed, inclusive process and John’s support encouraged one survivor to try eating for the first time in nine months.

The enthusiastic reception the workshops received enabled the research team – including John, who is co-applicant on the funding application – to hone the research question, but also to plan with confidence a project that will require considerable survivor input. The proposal, is more meaningful and patient/survivor-focused in its questions, research processes, planned milestones, outcomes and methods of dissemination than it would have been without the PPI. If funded, survivors will be central to the running of research workshops, in analysis, project management and in planning and designing the key output – a book of recipes, survivor commentaries on the suitability of new cooking techniques, and advice for the benefit of future patients.

The team has since secured funding from Beacon North East to run further workshops, enabling us to maintain our links and further develop the skills needed to maximise the potential of this collaborative project. Everyone’s expertise has been placed on an equal footing during this process, and as a result this project is ‘ours’ in the full sense. It belongs to everyone involved in its journey so far. And it has already spread beyond the immediate team; John now makes and shows off his cheese sandwich to his mates down the club, a big step for someone for whom the link between food and socialising had previously been broken. You can see and hear John – and the group – enjoying his cheese sandwich at <http://vimeo.com/groups/96345>

Contact: Duika Burges Watson and Sue Lewis
Email: duika.burges-watson@durham.ac.uk or sue.lewis@durham.ac.uk

People and Research South West

By Catrin Richards

People and Research South West is a collaborative initiative set up to support and signpost researchers and members of the public with an interest in public involvement in health and social care research locally. We are a partnership of NHS and academic organisations.

The initiative evolved from a scoping study on public involvement in research published last year. (http://hls.uwe.ac.uk/suci/Data/Sites/1/public_involvement_in_research_report_april_2010_final..pdf)

Although there are examples of active involvement in our area there was no co-ordinated approach locally and a danger of duplication of work. As many research projects link to more than one NHS trust and university and to NIHR research networks, it was decided that a more shared approach was needed. A Steering Group was set up of interested stakeholders to develop a co-ordinated local strategy. Although the Steering Group already had two patient partner representatives, one of our first objectives was to set up a Public Reference Group of members of the public already actively involved in research who could ensure that public/patient views could be heard and addressed by the Steering Group.

In May 2011 we invited applications to the Reference Group by advertising through our stakeholder networks and local voluntary and charitable organisations. We received 16 applications which we shortlisted to 10 on the basis of their experience in research. A patient research partner (who had not applied) chaired the selection process, which included a group discussion about public involvement in research so that we could observe how the candidates contributed and then each